

Transplant Chronicles

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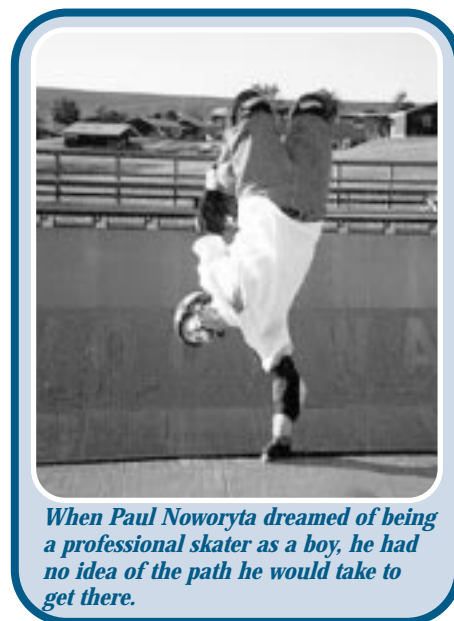
Kidneys, Determination and Extreme Dreams

By Paul F. Noworyta, Jr.

WHY ME? That was the question I had asked myself and God, over and over again. I knew in my mind there would be no quick reply to my question, no simple answer as to why at 19 years of age my body was being poisoned by the blood running through my veins. I was in the end stages of kidney failure before I knew what had happened to me and I was in desperate need of a kidney transplant. Oh sure, the doctors told me the name of some long scientific medical term that described my illness, but I wanted to know why it was me that this was happening to. Just a year ago I was graduating from high school looking forward to college and the possibility of becoming a professional

skateboarder. How could this have happened to me? I was young, healthy and full of life. I was invincible, or so I thought. I never thought I'd have such a tough battle ahead of me. A battle against myself.

After graduating from a Buffalo high school in 1987, I decided to go live with my father in Long Island where I could still skate everyday and attend college. Things were going fine: I was doing well in school, skating was a big part of my life and I was working a lot and making great money for a college kid. The only problem was that I had a constant headache for several weeks. Being a young stubborn person, I just dealt with it and never mentioned it to my dad. I attributed it to the stress of school and work. Then one day, while working in the warehouse, I could no longer read the orders coming off the printer. I had no choice but to tell my father that something was wrong. The vision in my right eye was a complete blur and I thought to myself, of course, I must need glasses—that's why I've had a headache for so long. How simple. So I was sent to an eye specialist who told me all of my blood vessels in my right eye had popped. I still didn't understand what was happening to me.



When Paul Noworyta dreamed of being a professional skater as a boy, he had no idea of the path he would take to get there.

The specialist sent me to the hospital where they took my blood pressure. I'll never forget the look on the face of the nurse who checked my pressure for the first time. Her expression was one of disbelief. She took it a second time...the reading was the same. My resting blood pressure was nearly 300 over 200. I was on the verge of a stroke and in for one hell of a ride. Every test and procedure was performed on me along with I don't know how many needles that were stuck in me. A week in ICU and the

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In this volume of Transplant Chronicles

- Is your cholesterol level low enough? Find out about the new guidelines on page 3.
- What sort of financial options are available for costly health care? Find out about coverage for nutritional counseling on page 4, about affording medications on pages 6-7 and 14-16, and even about fundraising on page 19.

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University of Nebraska Medical Center
Omaha, NE

Editorial Office:

National Kidney Foundation, Inc.
30 E. 33rd Street, New York, NY 10016
(800) 622-9010, (212) 889-2210
<http://www.kidney.org>

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Beverly Kirkpatrick
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Welcome to another issue of *Transplant Chronicles*. While reading over this issue the theme that kept popping into my head is “you can do anything.” Our cover story, about professional skater Paul Noworyta Jr., and our back page photo of Denny Ebright, who spent the 30-year anniversary of his kidney transplant skydiving, are living proof that life does not end with transplant, but for many it is a rebirth and it is where life begins.

Not to say that staying healthy doesn't come with some work, such as following a diet, doing exercise, taking medications and maintaining general health care. Many of these topics are covered in Laurie Williams's “Wellness After Transplant,” Kay Atkins's “Diets and Dollars,” Jennifer Hogg's “Preventing Injury” and David Post's article on controlling cholesterol. After reading this issue you will definitely have a good start to getting on the right track to life after transplant! Live life to its fullest and enjoy each day! **T_C**

Beverly Kirkpatrick
for the Editorial Board
transplantchronicles@kidney.org

Recipient Voices

What specific challenge are you most proud of accomplishing since your transplant?



Getting back to a normal family life and being able to work full time again.

— *Larry Stevens*

The requirement to take immunosuppressive medicine every day puts a burden on one's notion of freedom that gets harder, not easier, to deal with each year. There are times—especially when the Prednisone wreaks havoc on my skin or my bone density—when I just want to say, “I'm tired of taking these. I'm a six-antigen match and I'll take my chances.” In a managed care environment, my kidney transplant medications come from various sources, and the refills for them expire at various times. I've never succeeded at getting them all to renew at the same time. Managing the meds—and managing to take them (nearly) every day for 13 years, despite the secondary conditions they've induced in me, has been the challenge I'm most proud of meeting. My wife says I should maintain the perspective of the medicines' role in preserving my “gift of life.” It's not easy, day after day, to do that. But I soldier on, rewarded by the knowledge that our kids respect me for that.

— *John Shields*

My greatest accomplishment is giving birth to the sunshine in my life my daughter Brittany!

— *Ursula Aurelio*

Log on to www.recipientvoices.org for more responses, and to answer this issue's new question (on the back cover).



ask the pharmacist

New Cholesterol Guidelines for Adult Patients

By David J. Post, PharmD, BCPS

As summer approaches and our New Year's resolutions fade into a distant memory, something new is on the horizon! It's the latest guidelines from the National Cholesterol Education Program! This third national report on blood cholesterol (www.nhlbi.nih.gov/guidelines/cholesterol/index.htm) has some very important updates affecting transplant patients.

Your cholesterol has much to do with whether you will get heart disease. High cholesterol is a major "risk factor"—a condition that increases your chances of getting a disease. In fact, the higher your cholesterol, the greater your risk of heart disease or a heart attack. Heart disease is the number one killer of women and men in the United States. Each year, more than one million people have a heart attack and about half a million die from heart disease.

But not everyone understands what cholesterol really is and how it affects us. Here are answers to some of the most commonly asked questions.

What do all those cholesterol numbers mean?

Cholesterol should be measured at least once every five years in anyone 20 years old or older. A blood test called a "lipoprotein profile" can determine your cholesterol. This test, which is performed after a 9- to 12-hour fast, gives information about your:

- 1) Total cholesterol
- 2) Low-density lipoprotein (LDL)—"bad" cholesterol that is the main source of cholesterol buildup and arterial blockage
- 3) High-density lipoprotein (HDL)—"good" cholesterol that helps keep LDL in check
- 4) Triglycerides—another form of lipids, or fat, in your blood. The

table below shows the health risk categories for various levels of total cholesterol and LDL cholesterol. Cholesterol is measured in milligrams (mg) per deciliter (dL) of blood.

Total cholesterol	Category
Less than 200 mg/dL	Desirable
200-239 mg/dL	Borderline high
240 mg/dL or more	High
LDL cholesterol	Category
Less than 100 mg/dL	Optimal
100-129 mg/dL	Near optimal or above optimal
130-159 mg/dL	Borderline high
160-189 mg/dL	High
190 mg/dL or more	Very high

Because HDL protects against heart disease, higher numbers are better. Less than 40 mg/dL is low enough to be considered a major risk factor.

Triglycerides also can increase your risk of heart disease. Persons with borderline high (150-199 mg/dL) or high (200 mg/dL or more) concentrations of triglycerides may need treatment.

What is your risk of developing heart disease or having a heart attack?

In general, the higher your LDL and the more other risk factors you have, the greater your chances of heart disease or a heart attack. The major risk factors are:

- 1) Cigarette smoking
- 2) High blood pressure (140/90 mm Hg or higher, or lower but controlled by medication)

- 3) Low HDL (less than 40 mg/dL)
- 4) Family history of heart disease (in father or brother before age 55; in mother or sister before age 65)
- 5) Age (men 45 years or older; women 55 or older)

If you have two or more risk factors, you have at least a moderate risk of heart disease and should have your risk score (the sum of all your risk factors) calculated by a physician.

What are the risk categories, and what are my options?

If you have	You are in category
Heart disease, diabetes, or a risk score* of more than 20%	I. Highest risk
Two or more risk factors and a risk score* of 10% to 20%	II. Next highest risk
Two or more risk factors and a risk score* of less than 10%	III. Moderate risk
None or only one risk factor	IV. Low to moderate risk

* Your physician can calculate and score your risk.

The main goal of cholesterol-lowering treatment is to reduce LDL enough to decrease your risk of heart disease or a heart attack. The higher your risk, the lower your LDL goal will be.

There are two main ways to reduce cholesterol.

- 1) Therapeutic lifestyle changes (TLC). Changing how you live day to day is the first step toward reducing cholesterol. This includes going on a cholesterol-lowering diet (the TLC diet), increasing your physical activity, and controlling your weight. The TLC diet is a

Continued on page 4



Diets and Dollars

By Kay Atkins, MS, RD

With the changes that come with a transplant and the medications associated with it, there is a lot to learn about nutrition. Fortunately, many transplant recipients are entitled to nutritional education through Medicare or Medicaid, and there may be other financial assistance available for weight loss programs.

In January 2002, legislation became effective which covered Medical Nutrition Therapy for patients with diabetes mellitus or kidney disease (nondialysis). Both of these conditions can occur after transplant as side effects of the medications. Medical Nutrition Therapy (MNT) is a service provided by a Registered Dietitian (RD). The MNT session will be customized to your lifestyle and pattern of eating as well as disease. The session should include the following: 1) an initial visit with a dietitian who will review your dietary habits and attempt to include your lifestyle and physician's diet order; 2) instruction and education on how to change your dietary and lifestyle patterns to match what your physician has ordered; and 3) appoint-

ments to follow-up on your progress and make additional modifications as necessary.

To find out if you are eligible to use Medicare, you must have Medicare Part B, which covers Outpatient MNT for beneficiaries with diabetes and kidney disease (nondialysis). First, determine if you are eligible. Is chronic kidney disease or diabetes part of your diagnosis? If one of them is, your doctor will need to refer you to an RD who is a Medicare provider. To find an RD in your area, you may call 1-800-432-4040. Helpful Web sites are www.noridianmedicare.com and www.eatrightarizona.org. Call the dietitian to make an appointment. Be sure to bring your prescription and Medicare card to your appointment with the dietitian.

Medicaid coverage for MNT can be determined by calling your specific insurance plan. Each plan determines which condition/disease will be covered. Medicaid customer service can help you with this question.

Weight-loss programs have typically not been covered in the past. However with the recent increase in overweight and obese Americans, insurance companies now may offer some compensation. For example, a reduced fee for a gym membership or fees paid to weight loss organizations such as Weight Watchers. Overeaters Anonymous is offered at no or minimal cost. To access this information, you must call your insurance company to determine what your benefits are.

Another resource is the Weight-control Information Network (WIN). This

is a service of the National Institute of Diabetes and Digestive and Kidney Diseases, part of the National Institutes of Health under the U. S. Public Health Service. The WIN phone number is 1-877-946-4627. To use their Web site, go to www.niddk.nih.gov/index.htm and search for WIN. **T_C**

New Cholesterol Guidelines

Continued from page 3

low-saturated fat and low-cholesterol eating plan that calls for less than 7 percent of daily calories to be from saturated fat and for less than 200 mg of dietary cholesterol per day.

2. Pharmacologic treatment. If cholesterol-lowering medication is needed, it is used with TLC. Several types of medication reduce cholesterol, including "statins" such as simvastatin, bile acid sequestrants, nicotinic acid and fibric acids. Your doctor can help you decide which is best. Some medications you take to prevent transplant rejection can interact with these. Check with your doctor or pharmacist to ensure that you are taking the one best for you.

One of the key points in this latest update is that it places persons with diabetes at highest risk and identifies LDL of less than 100 mg/dL as optimal for them. All transplant recipients, especially those who are diabetic, should be proactive in determining their lipid profile and reducing their risk of heart disease. For a fuller explanation, consult your health care provider. **T_C**



Kidneys, Determination...

Continued from page 1

finding was that my kidneys were functioning below 10 percent. I was uncertain of what my future held or if I even had a future. One thing was for sure: I would lose the function of both kidneys soon.

After several years, Paul received a kidney transplant from his father, and after some difficulties (long stories in themselves) his health stabilized. Paul embraced his return to health wholeheartedly, becoming a DJ and dance performer in a hip-hop group in Buffalo.

After a few years, while living in Florida, Paul saw some extreme inline skaters on TV. Seeing these athletes made him nostalgic for his pre-transplant skating aspirations. He decided to buy a pair of skates (rather than a skateboard, which he used to use), and he went to meet other skaters in the area, becoming good friends with another skater named Elmer.

Paul began competing, and year after year he came close to top finishes on the amateur circuit—which would qualify him for professional competition—but every year something seemed to prevent this, whether injuries, close calls by the judges or bad luck.

It wasn't easy coming back home from the championships every year to tell everyone how I "almost" made it. I had serious thoughts of giving it up. It took so much out of me every year to prepare for this. Was it really worth it? Time was against me as an athlete. I was 32 years old and as it stood then there weren't any pros on the tour over 28.

2002 was here and I was telling myself this was do or die time for my skating career. But I had told myself that before.

I arrived in Los Angeles for the competition, along with 28 other skaters. We would compete for four spots on the pro circuit. The stands were filled to capacity. The time was now and I was the next skater up. My heart was pounding, my adrenaline was rushing but I kept a cool head and skated good. I completed my 50-second run without a fall. A big weight was lifted off of my shoulders. One down and one to go. My second run was even better than the first. At that point I felt I had skated the best I could and it was in the judges' hands. When they read

off the names of the top 10



Paul Noworyta returned to skating years after receiving his kidney transplant.



Paul refused to give up his goal of qualifying for the professional circuit of competition.

qualifiers, I was in sixth place and my friend Elmer was in seventh. It wasn't exactly where we needed to be, but it was good enough to get us into the finals. We were both excited to get this far, but knew we had to skate even better to make the top four. I was feeling very confident about my skating and had nothing to lose by skating the hardest I possibly could in the finals.

It was my turn to skate. I shocked my friends and myself by skating my absolute best I have ever skated in a competition, or possibly in my life, in that first run! Everything came together at the right time. Elmer skated just as good if not better than I just did in his first run of the finals. There was a break in the action to read off the standings after the first runs. I was in third place and Elmer was in second! I looked at Elmer and said, "Did I just hear that right? I'm in third and you're in second?" It was true. We were finally sit-

ting in contention for a dream years in the making. If the standings remained the same we were in, but there were still a few good skaters to go.

I chose not to watch the rest of the competition but instead went off by myself to give thanks to God and all of those who I had prayed to that watched over me this day. I had skated my best and I had given everything, and I mean everything, I possibly could give that day. The contest was over and the crowd gathered. All the skaters knew what was at stake. As the announcer read the results I sat alone to face my future. I was hoping it would be one of smiles and tears of joy and not one of a long flight back

to Florida, alone and disappointed. They read from tenth place down. All I wanted at that moment was not to hear my name until after fifth place was read. As the fifth place skater's name was read...my eyes were closed and chills went down my spine. It wasn't my name!

I had done it—in fact we both had done it! I finished fourth and Elmer placed third in the 2002 ASA Amateur World Championships of Inline Skating. For seven years we had skated together almost every day and this was the first time we competed in a championship contest and we both did it together! I was overcome with emotion and tears of joy did run down my face that day. I could hardly believe it was true. I had just validated the last 18 years of my life by accomplishing this goal. You see, I was always the best in the neighborhood or the best in the region but I could never make it into the "Big Leagues." All of the pain, the hard work, all of the disappointments and sacrifice, I overcame them all and proved to myself that in the words of Christopher Reeve, "Anything is possible." **TC**

How Do I Pay for the Drugs?

By Jean Rogers

I am 53 years old, am a legal secretary/assistant and live in Colorado. I was a Type 1 diabetic for over 40 years and didn't really have any complications until recently. The arteries in my heart became blocked and I had to go on dialysis because my kidneys were failing. I was introduced to the organ transplant program and was told I would be a good candidate for a kidney/pancreas transplant. At that time I was told that I would have to take anti-rejection drugs for the rest of my life if I was fortunate enough to receive a transplant. I did not realize then how unbelievably expensive these drugs would be.

I waited almost three years and finally received "the call" just in time in January of 2000. Three years have passed. I have had no rejection problems because I try to take good care of myself and always take my pills. I am still working because, fortunately, my company has insurance that pays for the bulk of the medicine I must take for the rest of my life. I have been working for over 30 years in a very stressful job. Someday I would love to retire, but it looks like my life will come to an end at my desk in my office.

I have tried everything I can think of to try to solve this problem. I have written several times to my representatives in Congress, I have called the United Network for Organ Sharing, I have talked to the transplant team at the hospital where I had my transplant and I have talked with my doctors. No one seems to have an answer. When my boyfriend and I were in Mexico recently, we checked with several pharmacies there and the prices weren't much better. I have been looking on the Internet to

see if there are cheaper drugs available from Canadian pharmacies. They do have the drugs that I take (including drugs for non-transplant issues which are quite a bit cheaper), but the cost of anti-rejection drugs is about the same as here in the United States, and I still cannot afford them. However, these pharmacies will mail the drugs directly to your house. At least at the moment, the Food and Drug Administration (FDA) and the Customs Department have intentionally chosen to look the other way as long as it is an individual (as opposed to a corporation or commercial entity) that is obtaining prescription drugs from Canada and bringing them into the United States. You can read more about this at <http://www.canadianmedsusa.com/disclaimer.htm>

Medicare will cover 80 percent of the immunosuppressants once you turn 65 and become Medicare eligible again—if you had Medicare at the time of your transplant operation. But God forbid for those of us who were working at the time of our transplant and were not on Medicare. If you are on Medicare only because of End Stage Renal Disease, the government will stop Medicare coverage 36 months after you leave the hospital following transplant surgery. This simply does not make any sense. I have heard horrible stories of people



The author, Jean Rogers, with her boyfriend Vis Jaunarajs.

skipping days to preserve their pills or simply taking the last pill because they can't afford any more, and they eventually lose their organ(s) and sometimes even their life. It seems our government would rather we go back on dialysis or lose our life instead of paying for the drugs for the life of the organ. I can't believe that a person's life is saved by having a transplant, and then there is no way to keep the organ or organs because that person can no longer pay for the drugs which have to be taken for the rest of his or her life. I feel bad for the organ recipient and even worse for the organ donor's family. Was all of this in vain? **TC**

About the Author

Jean Rogers lives in Lakewood, Colorado, with her longtime boyfriend. She is active in the fight to cure and prevent diabetes and plans to continue to be an advocate for herself and others for the rest of her life.

Be Careful, Because Others May Not

The National Kidney Foundation has received reports that patients have had their immunosuppressant prescriptions inappropriately switched to a non-bioequivalent product without the knowledge of their transplant team.

Your primary immunosuppressants should never be switched without your doctor's approval. For example, two different brands of cyclosporine—Sandimmune and Neoral—are available. They are not exactly the same and you should never switch back and forth from one to the other because your body absorbs them differently. Similarly, if you are on a generic Neoral, like Gengraf, you should not be given Sandimmune or a generic Sandimmune because they are not bioequivalent. Know how to identify your medications and contact your transplant team at once if your medication looks different!

Ask your transplant team for information about your medications. Ask your transplant pharmacist to give you information about medications when you get prescriptions filled. Your pharmacist plays an important role in your care. It's important to find one that is willing to take the time to discuss your medications. Do not be afraid to test a pharmacist's knowledge about immunosuppressants and bioequivalency. Never make changes based on what you read and never use information from the Internet without first checking with your transplant team. **TC**

Myth of Savings, Questions of Quality

By Dale Ester

Contrary to the popular mindset of big savings, the cost of immunosuppressants in Mexico is almost the same as in the US. Adding in the cost of travel, it can be considerably more. Though there can be some savings with nonimmunosuppressive medications, don't be fooled into thinking you found a bargain by packaging. Pharmacies may not pack medications in 30-day quantities, nor is the milligram strength the same. In addition, pills may be sold individually, without the protection of being purchased in a sealed container. Though factory-labeled, factory-sealed brand name medications are believed to be the same quality as medications bought in the US, the quality of generics is uncertain due to the potential lack of manufacturing oversight standards. It is important to make all decisions regarding your medications in conjunction with your transplant health care team, and not to purchase medications from other countries without this discussion.

The following government Web sites offer information about our nation's policies regarding the import of prescription medications into the US for personal use.

- U.S. Customs: www.customs.gov/xp/cgov/travel/alerts/medication_drugs.xml
- The Food and Drug Administration: www.fda.gov/ora/import/purchasing_medications.htm
www.fda.gov/ora/compliance_ref/rpm_new2/ch9pers.html
- U.S. State Department: www.travel.state.gov/mexico.html

Dale Ester of Glendale, Arizona, is a kidney recipient and volunteer Editor of NKF's newsletter, Family Focus. **TC**

Covering the Gaps

By Troy Zimmerman, NKF Director of Government Relations

Though Medicare does not generally cover self-administered drugs, there are some exceptions, including those for organ transplant recipients who were eligible for Medicare at the time of transplant (whether primary payer or secondary payer).

Many kidney transplant recipients qualify for immunosuppressive drugs coverage, since most individuals with end stage renal disease (ESRD) are entitled to Medicare coverage for dialysis or transplantation regardless of age ("ESRD beneficiaries"). Recipients of non-kidney transplants are eligible for Medicare coverage of their immunosuppressive drugs only if they had Medicare age or disability

status (receiving Social Security Disability Income) at the time of transplant.

Chronicle of Coverage

Immunosuppressive drug coverage was limited initially to 12 months post transplant, but a 1993 law expanded coverage to 36 months post transplant. More recently, the Benefits Improvement and Protection Act of 2000 ("BIPA") eliminated the 36-month limitation for Medicare aged and disabled (SSDI) transplant recipients who were Medicare eligible at the time of transplant. If eligibility is based solely on the beneficiary's ESRD status, coverage still ends at 36 months post transplant (if

a kidney recipient had Medicare ESRD status at the time of transplant and their 36 months has expired, but later attains aged or disability status, Medicare resumes coverage of the medications).

Remaining Coverage Gaps

Despite these extensions, gaps in coverage remain. The National Kidney Foundation is working with its congressional supporters on behalf of ESRD beneficiaries who are more than 36 months post transplant, and on behalf of aged and disabled Medicare beneficiaries who did not have Medicare at the time of transplant. Several bills have been introduced, which are summarized in the Government Affairs section of the NKF Web site (www.kidney.org). **TC**

Back to Work Resources

By Beth Witten, MSW

Social Security Administration Resources

A great resource regarding work for people with disabilities is the Social Security Office of Employment Support Programs (OESP) Web site, www.ssa.gov/work/. There are links to helpful resources for beneficiaries, advocates, students and employers. The 2002 Red Book on Employment Support (SSA Pub 64-030) is in the Resources Toolkit (www.ssa.gov/work/ResourcesToolkit/redbook.html), in print from local Social Security Administration (SSA) offices or from the SSA's toll-free number: (800) 772-1213.

Because few people who receive disability benefits ever return to work, the government wants to help willing and able people get back to work at a living wage. SSA says that working people with disabilities can qualify for Social Security Disability Income (SSDI) as long as they do not exceed the "substantial gainful activity" (SGA) level — \$780 in 2002; there is also an hours per month limit for the self-employed. SSA representatives should be aware of the rules about approving disability if someone is unable to work at a substantial level due to his or her disability. In the SSA "blue book" (www.ssa.gov/disability/professionals/bluebook/), kidney failure is considered a severely disabling condition.

Those receiving SSDI have a nine-month (not necessarily consecutive) trial work period (TWP) during which they can earn as much as possible and keep their disability check. Income under \$560/month (2002) doesn't count as a month of trial work. After the trial work period is over, if they regularly earn over the substantial gainful activity (SGA) level, their disability check should stop. [Note: People who receive disability payments are supposed to report their income to SSA.] SSA can approve

out-of-pocket "impairment-related work expenses" not reimbursed by anyone for services or supplies that allow someone to work. Examples include medications, doctors' and hospital bills, payment of a driver for work, modifications to a vehicle or home to allow you to work, medical devices, prostheses, etc. This deduction can reduce countable income below the SGA.

The TWP renews every five years. If someone has a health setback (same



diagnosis or a related diagnosis) that keeps them from working at the SGA level, he or she can get back on disability without an application and with no waiting period, provided it has happened within five years of the disability checks stopping. These benefits will last for six months while SSA determines disability.

New dollar amounts for 2003 can be found at www.ssa.gov/pressoffice/colafacts2003.htm

Ticket to Work Resources

The Ticket to Work program started with 13 pilot states in 2002. The rest will be added in late 2002 and 2003. Everyone between 18 and 64 on disability benefits will receive a "ticket"


with an explanation. Read about this program at www.yourtickettowork.com. SSA recently announced a program called Ticket to Hire to recruit more employers to hire people with disabilities.

Employment Resources

People with disabilities should look to government service or companies with 100+ employees that offer health insurance benefits. In 1998, according to the Small Business Administration, there were 100,000 companies with at least 100 employees. For temporary or part-time work, a temporary agency, such as Kelly, Olsten or Manpower (all of which have hired people with kidney disease) might be a place to look. Patients report these companies offer health benefits if someone works enough hours. Elizabeth Davies, MD, a transplant surgeon at Ohio State, refers patients that want to work to Wal-Mart. [Note: Wal-Mart has promoted itself as hiring people who are elderly and those with disabilities.] She said dialysis and transplant patients start off working part-time without benefits, but after the probation period, they get health benefits if they work enough hours. Check with your local Wal-Mart or any temp agency about benefits.

To help job seekers find work easier, the Workforce Investment Act created one-stop employment sites that offer services such as voc rehab, job services, labor department, etc. in one location. For the location in your area, see www.doleta.gov/usworkforce/onestop/

About the Author

Beth Witten worked as a nephrology social worker from 1978 to 1996, when she began working with the Life Options Rehabilitation Program. Beth has served as a volunteer with her NKF affiliate and with NKF nationally, including serving two years as the national president of the Council of Nephrology Social Workers. 

Transplant News Digest

from the editors of **Transplant News**

By **Jim Warren, editor and publisher**

Transplant News, edited and published by Jim Warren, is a twice-monthly newsletter for the transplant community focusing on developments in organ, tissue, eye and bone marrow procurement and transplantation. *Transplant News Digest* is written exclusively for quarterly publication in *Transplant Chronicles*. For more information about *Transplant News* visit: <http://www.trannews.com>



Jim Warren

NEW For monthly updates from the *Transplant News* editors, read *Chronicles Xtra* at www.recipientvoices.org

Bipartisan legislation easing financial strains on transplant recipients, live donors introduced in Senate

Bipartisan legislation introduced in early January in the House and Senate could ease financial strains on transplant recipients and living organ donors alike.

Under bills introduced by Senators Mike DeWine (R-OH) and Dick Durbin (D-IL), organ transplant recipients would receive lifetime Medicare coverage for their immunosuppressive drugs, and health insurers would be prohibited from raising premiums or imposing preexisting condition exclusions on living organ donors.

The bills would effectively close loopholes that weaken Medicare coverage for organ recipients and severely limit insurance options for donors. "Medicare treats transplant patients differently than other patients. The Medicare rules actually discriminate against transplant patients," said Senator Durbin in introducing the Comprehensive Immunosuppressive Drug Coverage for Transplant Patients Act of 2003 (S. 178). "For example, Medicare only pays for anti-rejection drugs for transplants performed in a Medicare-approved transplant facility. Most people are completely unaware of this fact and how it can jeopardize their future coverage of immunosuppressive drugs. Many are far too sick at the time of transplantation to research the

intricate nuances of Medicare coverage policy."

Senator DeWine noted that he and Durbin worked together in 2000 to pass legislation extending coverage of immunosuppressive drugs which contained "loopholes to the coverage that would finally be closed" by the new bill.

In a press release Durbin noted the existence of the following loopholes:

- * "Medicare does not pay for anti-rejection drugs for those patients who received their transplants prior to becoming a Medicare beneficiary. For instance, if a person receives an organ transplant at age 64 through his or her insurance plan, he/she loses immunosuppressive coverage when he/she retires and enrolls in Medicare for health coverage.
- * Medicare pays for anti-rejection drugs only for transplants performed in a Medicare-approved transplant facility.
- * End Stage Renal Disease (ESRD) patients qualify for Medicare on the basis of their needing dialysis. If ESRD patients receive a kidney transplant, they only qualify for Medicare coverage for three years after their transplant."

Under S. 178 the new Medicare policy would remove the above limitations and extend coverage to all Medicare beneficiaries who have had a transplant for as long as they need the drugs.

The Living Donor Protections Act (S. 186) contains provisions amending current protections contained in the Health Insurance Portability and Accountability Act assuring that living organ donors are not denied insurance nor are they subject to discriminatory premiums because of their living donor status.

"Quite simply, a brother who donates a part of his kidney to his sister should not be denied health insurance," DeWine said. "But tragically that is what often happens. Frequently, individuals who are living organ donors are denied health insurance or are restricted from the insurance market. Instead, we should celebrate living organ donors and remove obstacles and barriers for the successful donation of organs. Insurance should not undermine someone's decision to be a living organ donor."

The bill would amend three acts to provide health insurance protections for individuals who are living organ donors—the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code of 1986.

House passes legislation allowing organizations to pay some expenses incurred by living donors

The Organ Donation Improvement Act of 2003 (H.R. 399), authored by Representative Michael Bilirakis

Continued on next page

(R-FL), passed the House of Representatives in late February. The bill would allow the Secretary of the Department of Health and Human Services (HHS) to award grants or contracts to states, transplant centers, qualified organ procurement organizations or other public entities to help cover expenses of people who volunteer to become live organ donors. Organizations receiving the funds would be allowed to pay for travel and subsistence costs and specified incidental costs incurred by living donors. The bill allocates \$5 million a year, appropriated for each of fiscal years 2004 through 2008.

Despite some criticism from transplant groups, the bill retains a rather convoluted formula for providing the assistance. For example, assistance could only be provided if the donor lives in a different state than the recipient and the recipient's annual income does not exceed \$35,000 (may be adjusted for inflation in subsequent years).

The bill also authorizes \$15 million for fiscal year 2004 for carrying the HHS Secretary to carry out public awareness studies and demonstrations. The funding may be used to make grants to public and nonprofit private entities to conduct studies and demonstration projects for increasing donation, make grants to states to carry out awareness campaigns including increasing living donation and study, develop or enhance donor registries.

Frist, Durbin transplant bills would remove financial disincentives for live donation, create donor medal

With live organ donors now accounting for more than half of all organs available annually in the US, Congress is considering legislation that would remove financial disincentives donors may incur for making their generous gift.

Senate Majority Leader Bill Frist (R-TN), the author of the most

comprehensive bill, said it is time to "reimburse travel and other expenses incurred by living donors and their families" as a way of encouraging even more Americans to become live donors.

Frist's bill, the Organ Donation and Recovery Act (S. 573), contains a potpourri of provisions designed to increase organ and tissue donation, in addition to providing help for live donors.

Senator Richard Durbin (D-IL) introduced a less comprehensive bill in February, which also addresses removing financial disincentives for live donors. The DONATE Act (Donor Outreach, Network, and Timely Exchange Act – S. 376) also focuses on developing a national organ and tissue donor registry center, creating new donor public awareness programs, development of a donor medal and grants to hospital organ procurement coordinators.

Frist, a former heart transplant surgeon, also introduced a second bill, S. 572 — the Gift of Life Congressional Medal Act of 2003 — that would honor each donor or the donor's family with a commemorative Congressional medal.

The bipartisan bill "seeks to improve the overall process of organ donation and recovery, enhance our knowledge base of these fields, encourage novel approaches to this growing problem and increase the number of organs available for transplants each year," Frist said. "The bill also seeks to remove potential barriers to donation, while identifying and focusing on best practices in organ donation."

In addition to removing financial disincentives for live donation, the bill calls for a government run national registry of live donors.

"We must seriously evaluate the long-term health effects of serving as a living donor by asking the Institute of Medicine (IOM) to report on this issue and by establishing a living

donor registry to track the health of individuals who have served as living organ donors," Frist said.

The bill gives the Secretary of the Department of Health and Human Services the authority to award grants to states, transplant centers and qualified organ procurement organizations (OPOs) to provide "for the reimbursement of travel and subsistence expenses incurred by individuals toward making living donations of their organs" and for "incidental non-medical expenses that are so incurred as the Secretary determines by regulation to be appropriate."

Here are some of the other provisions contained in the two bills:

Hospital organ donation coordinators

Frist and Durbin both provide funding for demonstration projects designed to increase organ and tissue donation. In addition, HHS is authorized to award grants to qualified OPOs to establish programs for coordinating organ donation activities of eligible hospitals and OPOs in order to increase the rate of organ donation in hospitals.

Organ and tissue donor registries

Durbin's bill would create a national organ and tissue donor registry resource center to "advance the development, expansion and evaluation of state donor registries; facilitate exchange of information between state registries on a 24-hour basis and develop guidelines on a standard registry model including whether living donors should be included."

Frist is much more cautious. "We must seriously examine and improve the role of donor registries. These programs have an important role to play in improving organ donation rates and have been used with different levels of success in some states," he said. "However, a number of questions surrounding registries remain unanswered and their

effectiveness has not been fully evaluated.”

Institute of Medicine studies

Frist and Durbin both call for the IOM to conduct a comprehensive study of existing barriers to donation and best practices employed by OPOs, states and other countries.

However, Frist spells out in much more detail areas for IOM to address including mandated choice, presumed consent, existing state routine notification laws, the impact of requests for consent where registry listing constitutes express consent under state law and achieving higher donation rates, particularly among minority populations.

In addition, Frist calls for the IOM to conduct a second study to evaluate living donation and procedures such as assessing issues relating to informed consent and the health risks associated with living donation, including possible reduction of long-term effects.

Agency for Healthcare Research and Quality research initiative

The Frist bill authorizes \$5 million for the Agency for Healthcare Research and Quality (AHRQ) to develop “scientific evidence in support of efforts to increase organ donation and improve the recovery, preservation and transportation of organs.”

The agency is specifically directed to provide support for research and demonstration projects to “develop a uniform clinical vocabulary for organ recovery; apply information technology and telecommunications to support the clinical operations of OPOs; enhance the skill levels of the organ procurement workforce in undertaking quality improvement activities; and assess specific organ recovery, preservation, and transportation technologies.”

New York first state in US to develop strict guidelines for live donor liver transplants

Nearly a year after the tragic death of a live liver donor at Mount Sinai Medical Center, New York has become the first state in the US to endorse strict guidelines governing live donor liver transplants.

The comprehensive guidelines, which many expect will serve as a template for national guidelines, were developed by a panel of experts appointed by Antonia Novello, MD, Commissioner of the New York State Department of Health following the death of Michael Hurewitz on January 15, 2002.

Hurewitz, 57, a reporter for the *Albany Times Union* newspaper, donated a portion his liver to his brother Adam, 54, a physician who lives on Long Island. His death was attributed to poor aftercare because of a shortage of medical staff on his recovery ward. An investigation found that an inexperienced first year intern had been left in charge of 34 patients including Hurewitz.

Reacting to the finding, the new rule mandates that following donation, the live liver donor should receive 24/7 “continuous coverage by general surgery residents at the postgraduate-year-two level or higher, transplant fellows or physician extenders (nurse practitioners or physician assistants). In addition, between 6 p.m. and 8 a.m. and all day on weekends and holidays, donors should receive transplant service coverage from staff not covering other surgical and nonsurgical patients.

The 18-page report offers detailed guidelines in all areas of the donation beginning with calling for establishing an independent donor advocate team at the beginning of the process consisting of, at a minimum, “an internal medicine physician, transplant coordinator/nurse clinician, medical social worker with the partic-

ipation of a psychiatrist and/or ethicist as appropriate.” The guidelines also address informed choice, evaluation, liver transplant recipients, peri-operative care and facility support, and discharge planning.

Bill allowing donor card signers to exclude prisoners from getting their organs introduced in California

Following the death of a California inmate last December, State Senator Jeff Denham (R-Salinas) has introduced legislation (SB 38) that would allow people who sign a donor card or driver’s license to exclude prisoners from receiving their organs. An unnamed prisoner who received a heart transplant in January 2001 died last month after being described by prison officials as a “less than model patient.”

SB 38 would amend the California’s Vehicle Code to require the Department of Motor Vehicles forms relating to organ and tissue donation “to include a provision allowing the donor to indicate whether he or she desires to prohibit a donation to any person who is incarcerated in state prison or a county jail.” (The amended sections are 12811 and 13005).

“Donors want to know that their organs will go to save a life of a sick child or a productive member of our community,” Denham said, according to the *Sacramento Bee*. “We cannot afford to have people tear up their donor cards because they are afraid that their organs will go to save the life of a criminal while innocent children are left waiting on their deathbeds.”

The legislation was immediately criticized as unethical and illegal.

“We are opposed to any direction that would discriminate against any person or class of individuals,” Mary Wallace, public affairs manager of the California Transplant Donor Network (CTDN) told *Transplant News*. “We also oppose anything that

would limit people that medically need them from receiving organs.”

Bioethicist Arthur Caplan observed that prisoners are not the only people who might engage in “dangerous, risky behavior.”

“If people want to exclude prisoners, they better think hard about what prisoners they are talking about. Is a person who’s in on a bounced check on par with rapists, murderers and CEOs who steal millions?” Caplan said, according to the *Bee*. Caplan is chairman of the Department of Medical Ethics at the University of Pennsylvania.

California Department of Corrections spokeswoman Margot Bach explained that the heart transplant was only the second organ transplant given to a prisoner since 1996. She added that past court rulings require the state to provide necessary medical services to the California’s 160,000 inmates.

“If he had been denied the heart, he would have died much sooner than he did,” Bach said. “We would have been sued by his estate, and we would have lost.”

Study shows outcomes better for prompt kidney transplantation

The longer patients on dialysis wait for kidney transplants, the poorer their outcomes, according to a study in published in the January 15 issue of *Transplantation*.

The findings by researchers at the University of Florida Shands Medical Center in Gainesville underscore the advantages of transplantation compared with hemodialysis for patients in end-stage kidney failure and demonstrate the need for placing them on transplant waiting lists as early as possible, said co-author Bruce Kaplan, MD, director of kidney and pancreas transplantation.

“Dialysis keeps you alive, but you do not get the same benefit as transplantation,” he said.

In patients with End Stage Renal Disease, usually the result of diabetes or hypertension, kidney function typically is no more than 10 to 15 percent, noted Kaplan. These patients will die relatively quickly without dialysis or transplantation. The Florida study found that dialysis patients who wait for kidney transplants for two years have a three times greater chance of losing their grafts than those waiting less than six months. Kaplan’s team theorized that those on dialysis the longest were sicker at the time of transplantation and, thus, did not fare as well as those who were on dialysis for a short time.

“There is a 22 percent mortality in the first year of dialysis and a 60 percent mortality at five years,” said Mario Assouad, MD, a nephrologist at Baylor College of Medicine in Houston, Texas. “For patients on dialysis, the longer they wait, the more complications they develop.” As a result, they may require blood transfusions and other interventions.

Another key study finding was that transplant patients do not always have better outcomes if they receive organs from living related donor rather than from non-living donors. The advantage of having a living related donor “fades if patients wait for the living donor organ for two years or longer,” Kaplan pointed out.


“Not only is the quality of the donor organ important—and living donor organs are often ideal—if you wait long enough, recipients will not be able to take advantage of the great quality organ they’re getting because their health will have deteriorated,” explained co-author Herwig-Ulf Meier-Kriesche, MD.

Nonetheless, even if patients have to wait years for a transplant, the surgery “still confers tremendous benefit over dialysis,” stressed Kaplan.

Transplanted pig or human stem cells may work as a human kidney replacement

Results of experiments in mice suggest that kidneys created from human and pig stem cells might one day be used for human transplants, according to a December 23 advance on-line publication of *Nature Medicine*.

Yair Reisner, PhD, and colleagues from the Weizmann Institute of Science in Rehovot, Israel, transplanted undifferentiated or partially developed kidney precursor stem cells from human and pig embryos into mice to produce kidneys. The team was able to pinpoint the optimal time when these stem cells had the best chance of developing into functioning kidneys with a minimal risk for immune system rejection. They found that at seven to eight weeks for human and four weeks for pig, the tissues performed best as transplants. Earlier transplantation resulted in the growth of disorganized tissue that became non-kidney tissues, such as bone, cartilage or muscle, the investigators said. Later transplantation resulted in a high risk for rejection. But when transplanted at the optimal time, the cells developed into a kidney within ten weeks.

“The formed, miniature kidneys are functional, as evidenced by the dilute urine they produce,” the group wrote. “Considering the limited availability of human fetal tissue, pig kidney precursors could afford an unlimited source for renal transplantation. When tested in large animal models or in patients, our data predict that these early stage human and pig kidney progenitors should require less immunosuppression compared with that currently used in renal transplantation.” 

Taking Control of Your Health

By Laurie Williams, RN, CPTC

We estimate 180,000 transplant recipients living in the United States. The majority, meet the definition of “well,” i.e., more than one year post-transplant with stable organ function and a fairly consistent dose of anti-rejection medication. Most visit their transplant doctors only every 6 to 12 months.

Some recipients and primary care providers may not routinely address general health maintenance. Recipients may not call their primary care physician as readily as they did immediately after surgery. In this article we will discuss general health concerns to pay attention to as a well recipient.

New Medications. There are a variety of anti-rejection regimens for recipients depending on what organ was received and the protocols of individual transplant centers. In addition, you may take medications for underlying health conditions. When new medications are added, there is a potential for drug interactions. Most drug interactions are minimal; however, some have serious consequences including organ failure or death. Therefore, whenever a new medication is started or prescribed, whether over-the-counter or herbal, check with your transplant physicians! Keep a list of the current medications you are on and update it with each change or addition.

It is imperative to take anti-rejection medication as prescribed. There have been too many cases of lost organ transplants because recipients have altered their dose or stopped taking their prescribed dose of medication. Sometimes years after transplantation a recipient may feel so well he or she may be tempted to miss, skip or change medications. This is not a good idea. If you feel your medication dose should be decreased or changed, and or you are having problems paying for your medication, please notify your transplant team and work with them to

investigate alternatives. You are a partner in your care.

Heart Health. The most common cause of death, over the long term, for transplant recipients is cardiovascular disease. Causes of cardiovascular disease may include side effects from anti-rejection medications and lifestyle. Anti-rejection medications may increase blood pressure or have an affect on kidney function. Your kidneys help regulate blood pressure. High blood pressure and high cholesterol/lipid levels are associated with coronary artery disease, heart attacks, strokes and possible loss of the organ. Therefore it is important to routinely check your blood pressure. If you are



on blood pressure medicine, it is important to take it as directed and to have a blood pressure cuff or kit at home to monitor your blood pressure. A proper diet is necessary to control levels of cholesterol and lipids. Although you may have no dietary restrictions after transplantation, it is important to maintain a weight appropriate for your height. Obesity increases the risks of cardiovascular disease. Routine and regular exercise is key. If you are gaining weight, many transplant centers have dietitians who are available to help.

Diabetes. Diabetes mellitus (blood sugar problems) could be due to the anti-rejection medication, but in many cases it is due to diet and weight gain. Treatment of diabetes depends on the type. Sometimes diabetes is controlled with diet and exercise alone. Some recipients take oral medications, others take insulin shots. If you have blood sugar problems it is important to routinely check your blood sugar level. High blood sugars over a long time can cause problems with the kidneys, vision, nervous system and infection. Most routine lab work includes a test of blood sugar level. Your doctor or transplant team may ask you to fast prior to your lab work to obtain the most accurate blood sugar level. Obtaining lab work on a regular basis also helps in the detection of blood sugar problems.

Infection. Most recipients handle the common cold and flu virus just like any other person. However, high fever, unexplained pain, rash and diarrhea should be reported to a physician if they do not improve within 24 to 48 hours. Diarrhea and vomiting may affect the absorption of your anti-rejection medications, and if they persist for any prolonged period can affect the transplanted organ. Your transplant team usually provides you with a list of when to call the doctor. This list does not change with time. Your transplant team may also provide you with a list of vaccinations you should receive including recommendations about yearly flu shots.

Psychiatric Issues. You may face significant psychological challenges in returning to health. These issues often start long before the transplant and have to do with chronic illness. Fears of death, and other anxieties such as adjusting to changes in roles and functioning may be compounded by your post-transplant medications. Family

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Money for Meds

By Lara Tushla, LCSW

A transplant surgeon I work with says, "The surgery is easy; caring for the transplant for a lifetime is the challenge." While I doubt that the surgery is easy, it is often more cut and dried (no pun intended) than the ongoing efforts to maintain the transplant. This includes medications, work/school, health challenges and the numerous government agencies that you have to work within.

In addition to your anti-rejection medications, you may also take medicine to prevent infections, treat diabetes, lower blood pressure and cholesterol, improve anemia, prevent stomach ulcers, etc. As you know, this is all very expensive. National statistics indicate that immunosuppressants cost about \$1,000 per month. In my experience, this may be a good estimate for long term recipients, but a newly transplanted person often finds that their immunosuppressants run closer to \$2,000 per month.

If you are having trouble affording your medicines, please talk with your transplant team. They may know of resources that can help. Never skip a

dose or lower your dose without talking with your health care team!

Below are some ideas and questions that may help financially manage the medications which are so important to maintaining your health and the health of your transplant.

1. **Medicare:** Medicare has made some changes in coverage for immunosuppressants in the last few years. Part B will cover 80 percent of the cost of immunosuppressants (Medicare does not cover other medicines). You are eligible for the coverage if you had Medicare at the time of your transplant (as primary or secondary payer), if your transplant was done by a Medicare approved facility and if you currently have Medicare Part B. If you have Medicare solely due to having kidney disease, you will have the coverage for three years from the date of your transplant. If your Medicare is due to age or disability, there is no time limit on Medicare covering the medicine. (Note: Not all pharmacies are able to bill Medicare; check with your pharma-

cist. If they are not, ask your transplant team for a recommendation.)

2. **Medicaid:** The Medicaid benefits for prescription medications vary widely from state to state. Generally, Medicaid will cover your immunosuppressants the same way it will cover your other medicines. To apply for these benefits, please go to your local Medicaid office.
3. **For people whose incomes are limited,** but higher than the regular Medicaid guidelines, there are a couple of other programs which are important to know about. To apply for either of these programs, you can go to your local Medicaid office. The programs are:
- a. **QMB (Qualified Medicare Beneficiary):** Until April 2003, the allowable income is \$738 per month for a single person and \$995 for a couple. A single person may have \$4,000 in assets (\$6,000 for a couple). QMB will pay Medicare premiums (\$58.70 per month for 2003), co-payments and deductibles. It acts like a Medicare supplement.
- b. **SLMB (Specified Low-income Medicare Beneficiary):** The allowable income is up to \$886

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Resources:

In addition to talking with your transplant team about your needs, you can learn about various programs that are available to you using these resources.


- * www.rxassist.org: This Web site is sponsored by Volunteers in Health Care and is supported by a grant from the Robert Wood Johnson Foundation. On this site you can learn specific information about indigent programs, discount programs and state specific resources.
- * The Pharmaceutical Research and Manufacturers of America is the professional organization for drug manufacturers. On their Web site, www.phrma.org/pap/, you can research various drug programs.
- * The Medicine Program (www.themedicineprogram.com) will do some of the research to find the resources for each medicine. They charge a \$5.00 fee for each medicine.
- * Medicare has a lot of information about their benefits and State based programs. This can be accessed on their Web site, www.medicare.gov, or by calling 800-772-1213.
- * Each state has a Department of Insurance. One of the services these offices provide is information about insurance options available locally, including insurance policies, local Medicaid rules, and state specific resources.
- * State Children's Health Insurance Program (SCHIP) at 877-KIDS-NOW will help identify additional programs available to children.
- * Public libraries are wonderful sources of information. Most libraries will have computers with Internet access. They will have a copy of the *Physicians' Desk Reference* which provides information about medicines and contact information for the manufacturers. The librarian can teach you how to use these resources and others.

for a single person and \$1,194 for a couple). The asset allowance is \$4,000 for a single person and \$6,000 for couples. SLMB will pay the Medicare Part B premium.

4. **Private Insurance:** It is almost impossible to generalize about prescription benefits through private health insurance. Some questions to ask are:
 - a. *Is there a cost savings to using generic medications?* If so, ask your health care team if any of your prescriptions could be safely changed to generic alternatives.
 - b. *Do you pay a flat rate or a percentage?*
 - c. *Is there a mail order pharmacy benefit?* Many insurance plans encourage using mail order by providing three months of medicine for a lower co-pay. This is especially good for medicines that you expect to be taking for a long time.
5. **If you have more than one insurance,** can the second one be billed for co-payments for the first? If your pharmacy is not able to do this, you might check with a transplant specialty pharmacy to make sure your insurance is being maximized.
6. **Medicare supplements:** Supplements to Medicare, either from an insurance company or through Medicaid, will often cover the co-payments on immunosuppressants.
7. **There is a six month window** around your 65th birthday where you can apply for Medicare supplements where your medical history cannot be taken into account. You can not be turned down for coverage and your premiums cannot be raised due to any pre-existing conditions.
8. **Samples:** Some drug manufacturers offer samples to doctors' offices. Though immunosuppressants are generally not available in samples, you might be able to get a starter set of another medicine from your doctor. One example is blood pressure medicines, which are often changed.

If you have gotten a sample and the medicine does not work for you, you haven't spent money on a drug that you can't use.

9. **Indigent Programs:** Most drug manufacturers have programs to provide free medicine for people who have no prescription coverage and meet income restrictions. Most of the companies that make immunosuppressants will not provide free medicine if you have any prescription coverage, including Medicare, with the exception of Roche's CellCept Medical Needs Program. See the article on page 16 ("Find a Need and Fill It") and check with your transplant team to see if you might benefit from these programs.
10. **Discount Programs:** Drug manufacturers have recently started offering discount programs for people whose income is higher than the indigent program guidelines, but would still benefit from some assistance.
11. **Regional Programs:** Each area may have additional resources that are unique to them. This may include prescription assistance programs, local foundations, and other fund raising programs.

The most important resource you have in navigating the post-transplant experience is your transplant team. No one person can know the answers to all the questions or issues that arise—that is why there is a team of doctors, surgeons, nurses, social workers and financial coordinators. Don't be afraid, ashamed or nervous about asking questions about managing your medications. Together, we can usually make it work. 

About the Author

Lara Tushla, LCSW, has worked at Rush Presbyterian-St. Luke's Medical Center in Chicago for four years as the kidney and pancreas transplant social worker. Prior to that she worked as a dialysis social worker for six years.

Examples:

- A 67-year-old man received a heart transplant four years ago. He has had Medicare for six years due to his medical condition. He purchased a Medicare supplement when he turned 65. This covers his Medicare co-pays and deductibles, but does not have prescription coverage. Medicare will cover his immunosuppressants at 80 percent. His Medicare supplement will pick up the 20 percent co-pay, so his immunosuppressants are covered completely. He was enrolled in a state program that covered many of his other medicines, with only a small co-pay.
- A young woman with two small children received a liver transplant. She was unable to return to work for some time and was on long-term disability. She could not afford her COBRA premiums and lost her private health insurance. Until she was able to return to work, the transplant social worker encouraged her to apply for Medicaid benefits for her and her children. The disability income was under the Medicaid allowable guidelines and she got full coverage for herself and her children until she was able to return to work.
- A 30-year-old man received a kidney transplant from his mother. He is no longer working and has Medicare coverage. He had a serious episode of rejection because he was skipping doses of medicine since he was having trouble affording the 20 percent co-pay. We discovered that he had QMB (Qualified Medicare Beneficiary) benefits through Medicaid which acts like a Medicare supplement. We found a pharmacy that would be able to bill Medicare and his immunosuppressants were covered at 100 percent.

Find A Need and Fill It

By Robert McEwan, MBA


As Administrative Director of the Comprehensive Transplant Center at Johns Hopkins from 1996 to 2002, I became acutely aware of the damage that occurs to transplant patients when they cannot afford their medications. In cases like this, where some are ashamed to get help from their providers, people could lose their organ and possibly their life. Even when Medicare began covering the immunosuppressive medications for kidney transplants, they didn't provide any coverage for the other important drugs, such as those for hypertension, lipid lowering or diabetes. I was looking for a solution to this problem when in 1999, in an article in the *Wall Street Journal*, I learned about a program called MedBank in Savannah, Georgia. I traveled to Savannah, where the program had been in place for four years, and used it as a model for the one we started in Maryland in early 2000. That program helps not just transplant recipients, but all chronically ill, low-income patients who are under-insured or uninsured. The program has grown from zero to more than 17,000 patients (now covering the entire state of Maryland) in just over two years.



Medbank of Maryland has developed its own proprietary software, RxBridge, that is now available via the Internet. Health care providers that use this software can enter all of the information on a patient (whether a transplant patient or one with a chronic illness) once, and connect to any of the more than 100 pharmaceutical assistance programs forms. RxBridge will fill out the forms from the data entered

on the patient and print out all the forms to mail in to the companies. This includes information like income, assets, drugs prescribed, dosing and diagnoses (all required by pharmaceutical company forms). The software allows patient and application process tracking by a nurse, social worker or health care advocate, so that no one falls between the cracks.

Since most transplant recipients (and others who are chronically ill) are on 5 to 10 medications at a time, this type of computer automation saves time in providing help to patients. These pharmaceutical assistance programs were poorly utilized over the years because getting the necessary paperwork from companies and filling it out was so time consuming that few had time to do it all. Now, access to all of the programs takes a few minutes. You can learn more about Medbank of Maryland at our Web site, www.medbankmd.org

In May 2003, at the Transplant Administrators Forum in New Orleans, Medbank will launch the availability to obtain RxBridge at any transplant center in the country. 

About the Author

Robert McEwan has recently moved from his position as Administrative Director of the Comprehensive Transplant Center at Johns Hopkins to Medbank of Maryland, Inc., as CEO. He is also the Region 2 representative to the UNOS Transplant Administrators Committee and a member of the Maryland Governor's Committee on Service and Volunteerism.


Taking Control...

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members may also experience similar psychological challenges. It is important for the entire family to be aware of feelings of anxiety, despair, irritability, sleeplessness, nightmares or problems with concentration or interacting with others, to name a few. These may be temporary problems that will improve more readily with fast intervention. There are a number of ways to help with these issues including medication, counseling and maximizing family and social resources. Let your physicians or transplant team know if you have any mental health concerns.

General Health Maintenance.

Recipients have a slight increased risk of cancers due to the use of anti-rejection medications. It is imperative to undergo routine health care screenings. These include: routine history and physical exam, mammography, gynecologic exams and prostate exams including a PSA (prostate specific antigen). Colonoscopy should be obtained at age 50 or more frequently in patients who have colon problems. Regular dental visits are important, as is avoiding tobacco — both smoking and chewing. Regular brushing and flossing of your teeth will help prevent decay and gum disease. When you plan to be out in the sun for any prolonged period of time it is important to wear sun glasses to protect your eyes, apply sunscreen (with SPF 15 or higher) to prevent skin cancers and apply bug repellent during mosquito seasons to avoid West Nile Virus. Any spots on the skin that are changing in size, color or texture should be brought to the attention of a physician.

Last but not least, the reason for transplantation is to return to an active and more normal life style. Long-term survival has increased markedly during the last 15 years. Enjoy and appreciate life. Live it to the fullest. 



Robert S.
Gaston, MD

Living Donor Kidney Transplantation: Now More Than Ever

By Robert S. Gaston, MD

Organ transplantation is a reality because of living kidney donors (LD). The first successful transplants were kidneys donated from one twin to another in the 1950s. If these loving, committed people had been unwilling to take the risk of giving a kidney to a dying sibling, the entire field might never have developed. As our ability to prevent rejection improved over the years, and success with deceased-donor transplantation became more predictable, some speculated that living donors would become unnecessary. Quite the opposite has happened. Today, living kidney donors are more important than ever, and, in 2001, surpassed the number of deceased donors in the United States. In the next few issues of *Transplant Chronicles*, this column will be devoted to examining new developments in LD kidney transplantation.

After 50 years, why the renewed interest in living donors? To put it simply, several factors have converged at the same time. First is the overwhelming demand for kidney transplants. Amazing advances in immunosuppressive drugs and clinical care of recipients has made success rates in excess of 90 percent at one year commonplace, with over half of all transplants functioning longer than 12 years. More and more patients with chronic kidney failure now seek the life-saving benefits of transplantation. Even older patients (70 years and up) and those with other medical problems are now thought to benefit from a transplant. The result, as many of you know, is a waiting list that now includes over 50,000 Americans. Unfortunately, fewer than 10,000 kidneys from deceased donors become available each year, a number that has not changed appreciably for a decade or more. The


time spent waiting for a suitable kidney is multiplying, and can be as long as five years or more in some areas. For many renal patients, getting a kidney from an LD is the only real hope for timely transplantation.

Kidneys from living donors have always been more likely to succeed than those from deceased donors. Just over a decade ago, kidneys from LD might work 90 to 95 percent of the time, versus 65 to 75 percent success rates with kidneys from deceased donors. Although the gap has narrowed a bit in recent years (with over 90 percent of kidneys from deceased donors now working at least a year), there are still significant advantages to LD kidneys. While one-year outcomes are similar, the longevity of most LD kidneys still exceeds what can be expected with most non-LD kidneys by 5 to 10 years. In addition, a kidney from a live donor, on average, works better (lower serum creatinine) than kidneys from non-living donors. Being transplanted from a healthy donor in one operating room to a recipient in the next is much less stressful on a kidney than the process of death, recovery and organ preservation, regardless of the tissue match! This combination of better kidney survival and better function makes LD transplantation the gold standard for transplant outcomes, even in 2003.

The remarkable advances in immunosuppressive therapies have changed another aspect of LD transplantation. In the past, good outcomes could be predicted only when donors and recipients were “a good match” (i.e., family members). Now, tissue matching plays only a small part in selecting the best donor and recipient combinations. No longer do familial relationships define

the best results. The first step outside the “living-related” barrier was allowing husbands and wives to donate to each other, with success rates as good or better than even the best matched transplants from deceased donors. It is now commonplace to utilize distant relatives or friends as “living unrelated” donors, with full expectation of superb outcomes.

Finally, a radical new development in the care of living donors has emerged since 1995: the laparoscopic donor nephrectomy. Rather than an open procedure (leaving a rather large scar with four to six weeks of recovery time), many US centers now offer the laparoscopic procedure. The donated kidney is removed from the donor via an incision just large enough for it to pass through, with dramatically shortened recovery times. Although still a bit controversial, especially regarding the potential for long-term complications, many centers now offer the procedure as an option for most donors. Data indicate that availability of the laparoscopic operation has increased the willingness of potential donors to consider donating.

Thus, the combination of a lengthy waiting list for kidneys from deceased donors, better results, more potential living donors and speedier donor recovery have all contributed to rapid growth in LD transplantation. However, new questions and controversies have emerged. Is it really safe to donate a kidney? How aggressive should we be in trying to make LD transplantation an option for more people? Is it ethical to compensate living donors, financial or otherwise? In upcoming *Transplant Chronicles*, we will explore the answers to these and other questions. Stay tuned! 

Injury Prevention and Physical Therapy

By Jennifer Hogg, LATC

Half of all sports injuries can be prevented and are usually due to unsafe conditions, such as playing surface, equipment or weather conditions. A lack of appropriate physical conditioning necessary for the activity and most commonly returning to physical activity or play before an injury is healed or rehabilitated appropriately also contribute to many sports injuries.

Prevention is the best medicine and the following are some tips on preventing sports injuries:

- * warm up and cool down properly
- * plan safe training methods
- * prevent overuse injuries
- * stretch properly
- * hydrate properly
- * condition properly
- * watch for heat or cold environment related emergencies
- * watch for weather related emergencies like lightning

Unfortunately, sports injuries still happen. The severity of a sports injury is not easily determined. An injury that is incorrectly identified and one in which the athlete does not receive medical attention may become worse. The absence of pain does not signify the injury is not serious. When there is a sports injury causing pain, swelling or redness, do not try to “walk it off” as movement may aggravate the injury. If the injury is to the head, neck or back the participant should not move or be moved at all but instead have emergency medical personnel called immediately. If you experience any of the following from a

sports injury you probably need immediate medical care:

- * deformity of a limb
- * extreme localized pain
- * joint pain
- * altered level of consciousness
- * repeated vomiting or diarrhea
- * unequal pupil size
- * severe bleeding
- * breathing difficulty or irregularity
- * fluid leaking from the nose or ears
- * any eye injury affecting vision
- * chest pain



If you believe emergency medical care is not needed, returning to a sport even after the slightest of injuries may be inappropriate and sometimes just “sitting it out” on the sidelines may also be inappropriate. You must seek out medical attention immediately or very soon after a sports injury, as recovery time may be longer if proper care is delayed and you could experience increased or permanent damage. When in doubt, play it safe; do not return to physical activity and know the support systems that are available in the health care system.

When injured it is important to report injuries to the athletic trainer, if one is present. Otherwise, seek out a physician as soon as possible. After getting a physician diagnosis he may recommend physical therapy and if he does not, you may wish to ask if it would help you to recover quicker and stronger.

Once at physical therapy the process will help you to improve circulation, restore motion, relieve pain, prevent injury, strengthen muscles, correct deformities and promote healing,

allowing people to lead more active and independent lives.

You may be asked to perform functional tests prior to returning to physical activity or play. You should be able to demonstrate a pain-free full range of motion in the injured areas before being discharged from physical therapy.

An individual must be able to complete all functional tests pain free before they are

cleared to participate. One consideration prior to returning to physical activity is taping, wrapping or bracing the affected area. A poorly applied strapping or wrap can lead to blisters or skin irritation, place stress on other body parts and perhaps even increase the risk of injury of the region so the advice of a physician and or physical therapist is warranted when choosing to do so or not. **TC**

About the Author

Jennifer Hogg is the Coordinator of Sports Medicine Programs at the Northeast Rehabilitation Health Network in Haverhill, Mass.

Steps to Successful Fundrai\$ing

By Janice Hill

A patient facing a transplant has enough to handle. Add the news that the treatment and medications will cost more than the patient's ability to pay, and the typical response of being overwhelmed is understandable.

"'Overwhelmed' is a word I hear many times daily," says Carolyn Vannucci, Patient Referral Counselor at National Foundation for Transplants, who counsels transplant patients or family members concerning fundraising. "Most candidates feel a great deal of anxiety when realizing they will face significant expenses not covered by insurance. Frequently they do not know where to begin."

Although raising money may seem like an impossible task, especially for families already dealing with serious illness, it can be done successfully. To avoid legal and financial pitfalls, however, it is important to understand several key issues.

Legal/Financial Issues

Never place donations from the public in your personal checking or savings account. These funds could be considered taxable income or an asset that may make you ineligible to receive Medicaid.

Before asking for donations, you should be aware of regulations concerning charitable solicitations. Contact your state, county and city governments, or your legal advisor. Please note that individuals or businesses cannot claim a donation as a tax deduction unless it is made to an IRS-recognized charitable organization or institution. Many states require this IRS designation before permitting an organization to solicit charitable donations.

It may be possible to set up your own charitable organization, but the process can be complicated, lengthy, require some out-of-pocket expenses and probably only will receive IRS approval if

you plan to continue fund raising for other patients in the future. The first step is to prepare Articles of Incorporation and Bylaws and apply to your state to become a not-for-profit corporation (usually through the Secretary of State). Once recognized by the state, you can then submit an application (form 1023) to the IRS to become recognized as a charitable tax-exempt 501 (c)(3) organization.

You can avoid this process by working with an established, IRS-recognized charitable organization that specializes in assisting transplant patients with fund raising. A church or synagogue may also be able to set up a special fund to receive tax-deductible donations on your behalf. Before signing any commitment with an organization, it is important to ask for copies of their federal or state certification as a charitable, non-profit organization, an audited financial statement for the preceding year, and a list of references.

Fund Raising Success

The National Foundation for Transplantation was founded 20 years ago to assist with candidate fundraising. We have found that fundraising is always easier prior to the transplant, even if the money will only be used to pay for medications. It is possible to raise money after transplant, but volunteers and donors may not feel as great an urgency so it may take longer. Other suggestions we have include:

- * Recruiting as many committed, enthusiastic volunteers as possible. Begin by asking friends, neighbors, co-workers and family members. Also contact local civic organizations, churches, scouting groups, fraternities, sororities and schools.
- * Meeting with volunteers regularly to keep them motivated and informed.
- * Adequate time for planning events.
- * Beginning with smaller events and activities that require little planning or resources, and building up to more ambitious events.
- * Spending as little money as possible by getting everything for an event donated, or purchased at a discount, from local businesses.
- * Publicizing events through local media.

Although it is never easy, fundraising to help pay for transplant care and medications can be done successfully, providing it is approached with planning, proper legal and financial considerations and people willing and able to help.

About the Author

Janice Hill is the Manager of Communications for the National Foundation for Transplants in Memphis Tennessee, a nonprofit organization that assists transplant candidates and recipients in raising funds and acts as advocates for financial matters. **TC**

2004 U.S. Transplant Games: SAVE THE DATE!



The National Kidney Foundation's 2004 U.S. Transplant Games will be held in Minneapolis, Minnesota, from July 27 to August 1 next year. The Games, held every two years, are the largest sports event in the world for people with life-saving organ transplants. The event will commemorate the 50th anniversary of transplantation. For more information about next year's Games, visit the official Web site: www.transplantgames.com



Dennis Ebright takes his 30-year-old transplanted kidney on a sky diving tour. He says it was the most invigorating experience of his life and recommends it to all transplant recipients! (But check with your transplant team before taking the plunge.)

Let Your Voice Be Heard!



Log on to www.recipientvoices.org (the *Transplant Chronicles*' Web site) to read the answers to last issue's question, and provide your own answers to the new question:

Have you faced financial or insurance challenges along your transplant journey? Do you have creative approaches or solutions to problems you can share?

Log on, share your thoughts and view other readers' experiences. Also, check out *Chronicles Xtra*, available on-line only at www.recipientvoices.org

The transAction Council Executive Committee is conducting research to prepare a book called *Living with a Transplant — 1st Year After*. This book will look beyond short-term concerns, taking a broader perspective that includes the first year of adjustment to a new transplant. The book will be written in hopes that the content will be helpful to recipients as they think about choices to be made and options that are available to them in their experience of living with a transplant. Would you be able to take a few minutes to share your insights and experiences? Survey questions are available on the Web at www.transplantrecipients.org by clicking on "Share Your Experience." We would love to hear from you. Your responses will provide valuable information for our book.

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30 East 33rd Street
New York, NY 10016

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COUNCIL

(800) 622-9010
www.transplantrecipients.org

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